

# Utah Registry of Autism and Developmental Disabilities



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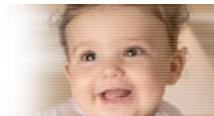
## Welcome!

The Utah Department of Health welcomes all to the third edition of the Utah Registry of Autism and Developmental Disabilities' newsletter! We want this newsletter to be useful for you and your family. Please send your comments or suggestions to us by phone at (801) 584-8547 or via email to [URADD@utah.gov](mailto:URADD@utah.gov).

## Awareness Campaign

NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES

*Learn the Signs. Act Early.*



On February 21, 2005, the Centers for Disease Control and Prevention (CDC), in collaboration with a coalition of national partners, launched a public awareness campaign to help parents learn more about the importance of measuring their child's social and emotional progress in the first few years of life. The campaign, "Learn the Signs. Act Early," is designed to educate parents about early childhood development, including the potential early warning signs of autism and other developmental disabilities.

"Our future lies with our most valuable resource – our children," said CDC Director Dr. Julie Gerberding. "Every child deserves no less than the right to achieve their full life potential. By recognizing the signs of developmental disabilities early, parents can seek effective treatments which can dramatically improve their child's future."

In the United States, an estimated 17 percent of children have a developmental or

behavioral disability such as an autism spectrum disorder (ASD), mental retardation, or attention-deficit/hyperactivity disorder (ADHD). Two-percent of children have a serious developmental disability, such as mental retardation, cerebral palsy, or an ASD. Recent estimates also indicate that up to one in 166 children have a condition in the autism spectrum.

In recent years, many programs and studies have indicated that early recognition of autism and other developmental disabilities is important because early treatment can improve a child's development significantly. The CDC campaign recognizes that parents often monitor their children's physical growth, and encourages parents to expand

those efforts to include social and emotional milestones.

"Parents naturally keep track of their child's height and weight, especially in the early years of life," said Dr. José Cordero, director of CDC's National Center on Birth Defects and Developmental Disabilities. "We want parents to add a few new items to the list of things they track. It's important for parents to note when their child learns to smile, how often their child smiles, when their child starts to speak, when their child begins to play, and how their child interacts with others. And if a parent notices anything that seems unusual, we want them to talk with their child's doctor or healthcare provider. In some cases, a problem may resolve with more time, but in other cases, a "wait and see" approach could delay opportunities to take helpful action."

Every child is different and develops at his or her own pace, but most children reach major milestones within a certain range of time (e.g., within four to six months of age, or by age one). The CDC campaign teaches

parents to pay attention to developmental milestones that children should reach by the age of six months, by one year, at two years, etc. such as turn their head when their name is called, respond when told "no", and begin make-believe play.

The CDC campaign also encourages parents to ask their child's doctor or healthcare professional about activities and steps that can be taken to foster their child's development. Parents can get information about local resources by calling 1-800-CDC-INFO. In addition to educating parents about important steps in a child's development, the CDC materials remind health care professionals to observe and measure when children achieve certain abilities, encourage dialogue between parents and health care professionals, and urge both parties to take immediate action when a delay in development is suspected. Free resources are available in English and Spanish for parents and health care professionals. For more information or to request materials, call 1-800-CDC-INFO (1-800-232-4656) or visit <http://www.cdc.gov/actearly>.

*"Learn the Signs. Act Early." is a collaborative effort of the United States Department of Health and Human Services, the Centers for Disease Control and Prevention, the American Academy of Pediatrics, the Autism Coalition, Autism Society of America, Cure Autism Now, First Signs, Organization for Autism Research, and the National Alliance for Autism Research.*

## Families' Corner

In this section of the newsletter, someone whose life has been impacted by an autism spectrum disorder or other developmental disability offers his or her perspective. If you are interested in writing an article for a future newsletter, please contact us.

Our parent contributor for this newsletter is Bill Crim. Bill is a community organizer and lives in Salt Lake City with his wife and two sons, Aaron and Nick.



## Knowledge is Power

The phrase "knowledge is power" is often used in politics and business to accurately describe the importance of information in traditional "win-lose" negotiations. But, it has never seemed as appropriate as when applied to the entirely different endeavor of parenting. Perhaps this is because I've never felt as powerless in any human interaction as I have as a parent, particularly one without the knowledge of what is causing his son's "odd" behaviors.

We knew that Aaron would have challenges when we adopted him at age three through the State foster care system. Aaron had severe developmental delays and the prognosis in his file was not promising. But the stability of a permanent home and excellent early education provided through Salt Lake City School District enabled him to start Kindergarten on grade level. We were thrilled.

By first grade, however, our sense of parental "power" started to fade away. At first it was just little things such as falling behind in school and having difficulty playing with other children. All of our efforts to help seemed to fall short. The older Aaron got, the more his "quirks" would impede his school and social experiences and the more they strained our relationship with Aaron as parents. We tried everything: rewards and token economies, time-outs and consequences, a new school. And of course we sought professional help. At first he was diagnosed with Attention Deficit Disorder (ADD). The medication helped a bit, but still we seemed to be fighting a losing battle.

I have never felt as powerless as I did in those few years. Aaron was getting older, and instead of getting closer and feeling more connected, we were drifting apart. I just couldn't understand why nothing we tried seemed to help. Our parental frustrations were making things worse at home, and school was becoming unbearable for little Aaron. His peer relationships had become so bad that he was forcing himself to throw-up so that he could come home "sick." When he stayed at school, we lived in daily fear of a phone call

from the principal with the latest acting out incident.

More doctors, more psychological evaluations and testing produced additional diagnoses of anxiety and depression. So we added some new medications, changed schools again, and gave it another go. But, the results were marginal and we still couldn't understand why Aaron was the way he was. He was now eleven, about to enter junior high, and we were terrified about his ability to survive his teenage years.

It was by accident (or fate) that we finally found the right path. After a particularly distressing acting out incident, we started calling everyone we could think of. One person referred us to a program for children with behavior problems offered through Valley Mental Health. We were ready to try anything, with or without a clear picture of what was causing Aaron's problems. Another set of testing and evaluations produced a surprising result: information that has changed everything for the better.

I didn't know it at the time, but learned that autism was not a single diagnosis, but a spectrum of disorders with a wide range of severity. We learned that Aaron has a form of "high functioning autism" or Asperger Syndrome. Suddenly things started to make sense. A flood of knowledge from capable health care providers, books, Internet resources, and other parents totally changed our sense of "power" to parent Aaron. Almost overnight the stress and frustration of parenting changed. We had a framework to understand why Aaron could talk incessantly without noticing whether or not anyone was still listening, or why he would develop intense fascinations with odd objects, only to discard them once he got them. We learned why loud noises and chaos caused him to "lose it" and we now understood why his reality was so different from our own.

Most importantly, this knowledge empowered us to understand and relate to Aaron in a totally new way. Our expectations shifted to match Aaron's abilities. Our frustrations turned into appreciation (for the most part) of his uniqueness. Understanding who Aaron was

allowed us to be patient more often and to work with him rather than against him.

Aaron doesn't suffer from anxiety or depression anymore. He still has many challenges, and we are far from perfect parents, but the future is less scary now. Aaron's strengths are becoming more apparent, and we have a wealth of experience, information, and tools to deal with his problems. It's funny in some ways that all of this change hasn't come from some new drug or therapy but simply from knowledge that has changed our understanding and our behavior. I guess knowledge really is power.

## What's New?



This section of the newsletter will include a summary of a recent research article that looks at autism spectrum disorders or other developmental disabilities. If you are interested in reading the entire article, you can get it from your library, or contact us and we will help you get a copy.

**Article Name:** Possible Association Between Autism and Variants in the Brain-Expressed Tryptophan Hydroxylase Gene (TPH2)

**Authors:** Hilary Coon, Diane Dunn, Janet Lainhart, Judith Miller, Cindy Hamil, Agatino Battaglia, Raffaella Tancredi, Mark F. Leppert, Robert Weiss, and William McMahon

**2005**

Journal reference American Journal of Medical Genetics Part B: Neuropsychiatric Genetics 9999:1–6 (2005)

Serotonin is an important chemical transmitter that plays a role in sleep, memory, digestion and other brain and body functions. It may also play a role in autism. There are three lines of evidence that suggest the importance of serotonin in autism. First, serotonin blood levels are increased in the blood of children with autism. Second, excessive repetitive behaviors have been successfully treated with medications that increase serotonin availability for serotonin receptors in brain cell synapses. Finally, some studies have found a relationship between autism and a

gene that codes for the serotonin-transporting protein found in brain cells.

Now, scientists in Utah and in Italy have reported an association between autism and single nucleotide changes in a gene related specifically to the production of serotonin in the brain. (A nucleotide is a basic building block of DNA; the four possible nucleotides are adenine, guanine, cytosine or thymidine.) Furthermore, the association is stronger for subjects with both autism and repetitive behaviors. The gene is known as TPH2. It codes for the enzyme tryptophan hydroxylase and controls the production of serotonin in the brain. TPH2 is located on chromosome 12.

The study focused on a sample of 74 children from Utah and 14 children from Italy, of which 86 met ADI and ADOS criteria for the diagnosis of autism. The remaining two children were diagnosed with Asperger. The DNA sequence for the TPH2 gene in the autism group was examined for variation and compared to a group of 95 individuals without autism.

This is the first published study of TPH2 in autism and the results add support to the hypothesis that serotonin is a factor in the development of autism. The strength of the finding is modest, perhaps because TPH2 is only one of several causal factors. Also, it is possible that the positive findings are the result of sampling error. Thus, additional studies are needed in other samples of individuals with autism and by other laboratories. If such future studies find similar results, TPH2 can then be investigated in cell cultures and in mice to better understand the role of TPH2 in brain development. Knowledge of TPH2 could lead to new insights into the biology of autism and to potential new treatment approaches.

## A Reminder and a Request for Help!

Please visit our website and tell others about it: [www.health.utah.gov/autism](http://www.health.utah.gov/autism) We update it monthly. If you would like something on the website that you don't see there, please contact us and let us know.

Finally, URADD needs your help! We want all Utah families affected by an autism spectrum disorder or other developmental disability to know about us. If you know other families who fit this description, please share this newsletter with them, or tell them about our website.

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## Become Part of the Utah Registry of Autism and Developmental Disabilities!

The Utah Registry of Autism and Developmental Disabilities is always looking for Utah residents who have an autism spectrum disorder to become part of the registry. The registration form is available online:

<http://health.utah.gov/autism/Registry.htm>

You can also request a registration form over the phone, by fax, or by mail.

### To contact us:

#### Mailing Address

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